

COMPLEMENTARY THERAPIES AND CANCER CARE: **Report of the Research Symposium**



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London

Organised by the Complementary Cancer Care Charities Partnership

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May 2005

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1 Introduction

1.1 Background

In June 2004 the Complementary Cancer Care Charities Partnership (the Partnership), in association with the National Cancer Research Institute (NCRI) hosted a research symposium focused on complementary therapies for cancer care. It was the first of its kind in the UK. The primary goal of this symposium was to inform the development of a rational and achievable agenda for complementary therapies and cancer care research in the UK. This was made possible by the support of the National Cancer Institute (NCI) of the National Institutes of Health (NIH) in the USA.

This report of the symposium is designed to serve as a companion to the video recording of presentations (provided on CD-ROM) and selected presentation abstracts as published in *Complementary Therapies in Medicine*, (June-September 2004), and included in this pack. Further copies of the symposium proceedings can be downloaded freely from the website of The Prince of Wales's Foundation for Integrated Health at <http://www.fihealth.org.uk>. There is also a link to the video presentation on the website.

1.2 Complementary Cancer Care Charities Partnership

Five charities are pursuing their common interests in complementary therapies and research through the Partnership. They are:

- Breakthrough Breast Cancer
- Bristol Cancer Help Centre
- Macmillan Cancer Relief
- Marie Curie Cancer Care
- The Prince of Wales's Foundation for Integrated Health

His Royal Highness The Prince of Wales has been instrumental in encouraging these charities to work together and develop this common agenda on behalf of patients, health professionals and the public. This research symposium was one outcome from the recently formed charity partnership. The organisers are particularly grateful for The Prince's

continuing commitment to the principles and practice of integrative health care and for taking the time to address the symposium. Both the CD-ROM and the abstracts feature the full speech made by HRH The Prince of Wales.

1.3 Terminology

The phrases 'complementary therapy' and 'alternative therapy' are sometimes used interchangeably. They are both terms used for treatments that previously were not part of conventional medicine, but there are significant differences between them. In the UK, the term 'complementary therapies' is usually used to describe those therapies that can work alongside and in conjunction with orthodox medical treatment. Alternative therapies are those that are used instead of orthodox medical treatment.

Other terms sometimes used to describe complementary and alternative therapies include:

- 'Unconventional' or 'unorthodox' therapies
- CAM (Complementary and Alternative Medicine)
- 'Integrated healthcare', 'integrative therapies' or 'integrated medicine'.

'Integrative care', harnessing the best of orthodox medical treatment with complementary approaches to care, is attracting growing interest. It means taking a whole person approach and using a wide range of therapeutic modalities rather than a limited few. This is partly driven by patient demand for a model that complements conventional medical care, and partly by health professionals' growing awareness of the benefits of using a holistic model in a healing environment. Integrative care may provide the most sustainable and satisfactory model for planning and delivering services.

This symposium provided a useful forum to look beyond individual therapies and consider the concept of integrative care. Whilst acknowledging the vital importance of orthodox medical treatment, it is evident that emotions, relationships, mind, body and spirit play a central role in health, rehabilitation and wellbeing.

The focus of this symposium was predominantly on therapies used alongside conventional practice: complementary therapies. This term and CAM are used throughout the report depending on the

preference of the speaker and whether or not there was a need to include alternative therapy approaches in the discussion.

1.4 Goals of the symposium

Recognising the need for rigorous scientific research in this field, the symposium organisers created this forum to support the continuing development of the science of complementary cancer care.

As cancer patients continue to explore complementary treatments and practices, the need for reliable scientific data in this area increases. Complementary therapy research often involves novel concepts and claims. Many of the therapies use complex systems of practice that need systematic, explicit and comprehensive knowledge and skills to investigate them. Health professionals are being asked about complementary approaches to cancer care and commissioners are seeking evidence of efficacy and effectiveness to inform practice.

Researchers, health professionals, complementary therapy practitioners and users (patients) all share a common goal: to advance our knowledge of effective and safe complementary approaches in cancer care.

In the words of one symposium participant, the event presented an opportunity for the cross-fertilisation of ideas and the sharing of information, experience and resources between the UK, Europe and the USA, as well as the identification of priorities for the future.

The specific aims of the symposium were to:

- Provide an overview of the usage and specific types of complementary therapies commonly used in cancer care
- Provide a forum for leading international researchers and clinicians to debate current and future challenges in complementary therapies and cancer care
- Help to inform the work of the recently established NCRI Complementary Therapies Clinical Studies Development Group
- Exchange experience and ideas between the UK and the USA about research-related issues
- Enhance research opportunities and develop a

better support network for both experienced and new researchers in this field

- Identify the necessary forward steps in order to sustain the momentum of progress achieved to date

The symposium brought together representatives of various groups involved in complementary cancer care.

1.5 Participants

More than 140 people were invited to attend. Researchers, oncologists, palliative care physicians, general practitioners, specialist nurses with an interest in research, CAM practitioners, psychologists, health service researchers and policy makers were all well represented. So too were users and consumers, the major cancer charities, information and service providers and major cancer research bodies and funders.

National and international experts, particularly from the USA, were brought together to inform the audience and each other about their own activities to support further development in this scientific field. Discussions included the identification of major obstacles that have hindered this process and possible solutions, prioritising the important issues for the future and the development of collaborative activities and future partnerships.

As some of the issues are not unique to cancer care, representatives from related and relevant associated fields, for example, caring for people with chronic illnesses such as arthritis, were invited to help shed light on issues such as self-management. Lessons learned from other disciplines may help guide the development of research and good practice models for complementary therapies and cancer care.

1.6 Symposium sessions and structure

After overviews of UK and USA activities in the field, sessions focused on the following key themes:

- Infrastructure and funding research
- Research issues and themes in specific therapies such as acupuncture, homeopathy, herbal medicine, nutrition and nutraceuticals

- Development of research programmes, including examples from both the UK and the USA
- Challenges relating to research methodologies in complementary cancer care research such as study design, measurement tools and the placebo response
- Developing and finding ways to distribute reliable, up to date and easy to access information about complementary and alternative cancer therapies for health professionals and patients
- Crafting an agreed agenda for complementary therapies and cancer care, which identifies the challenges and potential national and international collaborations necessary to reach collective goals in the most timely manner

The agenda included presentations addressing these issues from the user's perspective as well as the clinician's. Appendix B contains a list of the symposium presentations.

2 Overview from the UK

2.1 Growth of complementary cancer care

The speaker identified significant developments and challenges facing complementary cancer care in the UK. Complementary therapies are increasingly recognised as useful adjuncts to orthodox cancer care. Most hospitals and hospices offer their patients (and often staff and carers too) at least one complementary therapy. In addition, the voluntary sector is providing such therapies in many areas. Surveys indicate that most cancer services offer a choice of complementary therapies, mainly touch, mind-body therapies and acupuncture.

In recognition of this increased provision, The Prince of Wales's Foundation for Integrated Health published *National Guidelines for the Use of Complementary Therapies in Supportive and Palliative Care* in May 2003. The guidelines were developed, jointly with the National Council for Palliative Care, to encourage best practice and to help those wishing to set up services. It is important to note that no single model exists for the role of complementary therapies in cancer care and there may be overlap between different models in use.

It is clear that medical practitioners and service commissioners seek evidence of efficacy to establish what works now and for the future. They recognise that complementary therapies have a place in supportive and palliative care. It is also acknowledged that there is a need to encourage orthodox health professionals to reassess the basic tenets of good care, such as touch, talk and time and a holistic approach to care within a healing environment.

2.2 Reasons for usage

The reasons why users are drawn to complementary therapies are increasingly

understood. Some of the main reasons given for usage are:

- To help relieve symptoms from the cancer itself or its treatments
- To improve overall wellbeing and quality of life
- The ‘touch, talk and time’ offered from therapists is comforting
- To provide a means of allowing the patient to feel more in control of their situation (self help)
- Possibly to increase survival and seek ‘cure’

Many people are also attracted to using them by the hope that certain therapies may boost the immune system and help ‘fight the cancer’.

Impact on the disease process does not tend to be advocated for the therapies used as complementary; rather, alternative therapies may be used in this capacity, although to date these remain chiefly unproven. In the UK there has been very little good quality research on any therapies that are thought to hold promising treatment value.

2.3 Research and funding in the UK

Funding for CAM research comes from government, academic and charitable or voluntary organisations, but remains a very small percentage of overall cancer research expenditure. Recent initiatives, such as the establishment of the National Cancer Research Institute (NCRI) Complementary Therapies Clinical Studies Development Group, aim to address this imbalance. Under the NCRI model, CAM research could increase our knowledge about cancer prevention, treatment and control, survival and outcomes. Currently, however, research on prevention and treatment, and medicinal and nutritional approaches, is minimal. The main areas of research activity include touch, mind-body therapies and acupuncture for supportive care.

Factors contributing to this shortage of funding were said to include:

- A lack of effort to validate efficacy
- A failure to focus on specific research questions
- A lack of clarity in research goals
- Insufficient exploratory and pilot work
- Inadequate understanding of how complementary mechanisms work and their theoretical framework

Collaboration across research and practice communities is essential to understand the role and value of the therapies and to help design trials accordingly. This is increasingly happening in the UK. Ultimately, perhaps, research into complementary therapies will be driven by what patients themselves want and need. Involving cancer patients and others who are affected by cancer – such as carers and health professionals – to help measure areas of most concern to patients, is vital to help develop better methodological tools and ensure scientific rigour. In addition, a research evaluation collaborative network is needed to ensure that clinical practice is informed by high quality research.

2.4 Developing reliable sources of information

Patients and health care professionals need the right information to understand that not all therapies are necessarily safe just because they are described or perceived as natural. Some therapies may react adversely with conventional treatments.

The UK research community, and its funding bodies, should respond to the need for reliable information from reputable sources for both health professionals and the public on the safety, efficacy and interaction of therapies. This approach will foster increased safe and appropriate use of complementary therapies and improve orthodox care. There is a great willingness in the USA to make information freely available worldwide. The Memorial Sloan-Kettering website information resource on herbs, botanicals and other products (<http://www.mskcc.org/mskcc/html/11570.cfm>) is a notable example. The UK’s Research Council for Complementary Medicine, supported by the Department of Health, is developing a database of CAM in cancer care designed for patients and health professionals. This resource has great potential for providing up to date information in this area. Tapping into reputable databases such as these helps build an authoritative global network of information resources for patients and health professionals alike. (See Appendix A for a list of useful resources.)

3 Overview from the USA

3.1 Infrastructure and funding research

This session explored examples of activities which have helped to identify the major obstacles to developing infrastructure and successful funding support for complementary cancer care research. The Director of the National Cancer Institute's Office of Cancer Complementary and Alternative Medicine (OCCAM) described several activities initiated by OCCAM to address obstacles and support the development of the foundation of these fields.

3.1.1 National Cancer Institute - CAM history and the role of OCCAM

The National Cancer Institute (NCI) has been evaluating complementary and alternative approaches in cancer since the 1940s. The Gerson regime, Hoxsey and the use of Laetrile in the treatment of cancer are among the approaches it has studied. In 1991 the NCI established its Best Case Series (BCS) review programme to evaluate case reports of potential new cancer treatment from CAM domains. Examples of topics that came through this programme include antineoplastons and the Kelly/Gonzalez Regime.

As a result of the interest in CAM within the NCI, the OCCAM was created by NCI senior leadership in 1998. The Office was established to coordinate and enhance activities of the NCI in CAM research. The OCCAM is administratively under the Office of the Director with the goal of increasing the amount of high quality cancer research and information about the use of complementary and alternative modalities. It aims to achieve this by:

- Promoting and supporting research into CAM disciplines and modalities
- Coordinating NCI's CAM research and information activities
- Coordinating NCI's collaboration with other governmental and non-governmental

- organisations on CAM cancer issues
- Providing an interface with health practitioners and researchers regarding CAM cancer issues

Since OCCAM's creation, the NCI's research expenditure for CAM has more than quadrupled from \$28.2 million in 1998 to \$119.6 million in 2003.

3.2 Research development and support activities

3.2.1 Competitive research proposals

In early analyses of the research funding process in cancer CAM it became clear that several issues impeded the receipt and funding of grant applications. One issue is the lack of competitive research proposals. In order to address this, OCCAM created a series of Technical Assistance Workshops to aid researchers in the preparation of their applications to the NIH for funding support. These workshops are designed for investigators who are new to cancer CAM research and/or who are struggling with the NIH grant application process.

The workshops provide researchers with an opportunity to enhance their knowledge of the NIH grants process and funding opportunities. Participants learn about the different types of funding, grant mechanisms and announcements as well as the grant application process, with details about preparation, development, assignment, review and award issues and an emphasis on issues unique to cancer CAM research. The workshops include presentations and discussions with: scientific staff from the NIH; experienced researchers who have been successful in developing and finding funding support for CAM research programs; and representatives from private organisations that provide research support for cancer CAM projects. The workshops have resulted in a document, *Strategies for Success: How to Write a Grant in Cancer CAM Research*, which is available through OCCAM or can be downloaded from the OCCAM website http://cancer.gov/cam/research_grants.html.

3.2.2 Research methodologies in cancer CAM research

OCCAM also identified the lack of appropriate research methodologies as a substantial obstacle

hindering the advancement of complementary cancer care research. Whether one is reviewing the literature to guide clinical practice or interested in conducting further research in CAM, it is critically important to understand the unique challenges within CAM research methodology. As the field of CAM research has developed, the need for well-developed research methodologies has become apparent. In recognition of this need, OCCAM established a series of expert panels to assess and critique the state of the science in research methodologies in CAM cancer research. Panellists from both conventional and CAM research apply their knowledge and expertise to specific topic areas within cancer CAM. They then identify the major methodological challenges in cancer CAM research and propose potential solutions. It is OCCAM's expectation that this process will assist grant applicants by illustrating the types of issues that should be addressed in cancer CAM research proposals. Please see Appendix A.3: *Expert Panels in Cancer CAM Research: Developing the State of the Science in Research Methodologies. Expert Opinions on Methodology: Development of Cancer CAM Symptom Research* by the Office for Complementary and Alternative Medicine Expert Panel on Symptom Research

3.2.3 Surveys and focus groups

Research in CAM topics often requires expertise and skills appropriate to the project. Assembling the right team is essential for both preparing a competitive application as well as conducting the actual research project. OCCAM has taken steps to identify some of the barriers in conducting cancer CAM research by reaching out to both the cancer researcher and CAM practitioner communities. OCCAM has conducted surveys and focus groups of both CAM practitioners and CAM cancer researchers, as well as focus groups of cancer patients about CAM information resources. These activities help inform the development of announcements, initiatives and other programmes to address the perceived barriers to the conduct of rigorous cancer CAM research.

Through these activities OCCAM strives to attract expert researchers from cancer communities to apply their knowledge to CAM topics, as well as attract experts from the CAM research and practice communities to apply their expertise to cancer topics. OCCAM endeavours to seek out and

support both these communities as essential partners in the development of this field.

3.2.4 Information resources

The NCI produces fact sheets and summaries of the literature on various CAM therapies. These are available via the OCCAM website at <http://cancer.gov/cam>.

4 UK Funding, Infrastructure and Perspectives

Representatives from the National Cancer Research Institute (NCRI), the Department of Health (DOH) and major cancer research funders discussed some of the lessons they had learned and the major issues of concern over funding and infrastructure of complementary cancer care research. They highlighted some of their strategies to address obstacles in the development and support of this relatively new area of research.

4.1 National Cancer Research Institute

The NCRI was set up to provide national strategic planning. It serves as an umbrella body to enable the cancer research funders to identify areas that require more focus, such as palliative care and CAM. It also provides evidence-based support to inform future areas of research and brings a new culture of dialogue, specifically with the creation of the Complementary Therapies Clinical Studies Development Group. (See Appendix A: Useful Resources.)

4.2 Department of Health (DOH)

The Research Capacity Development Programme is a national project funded by the DOH. It began in 2002 and provides personal awards and funds academic infrastructure to support research development within the NHS. Under this programme there is a research scheme for Complementary and Alternative Medicine (CAM) aiming to develop research in this field and achieve a critical mass of researchers. More information about this programme can be obtained from the DOH website, <http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/fs/en/>.

4.3 Medical Research Council (MRC)

Presentations included a description and discussion of the MRC document developed in April 2000, *A Framework for Development and Evaluation of RCTs for Complex Interventions to Improve Health*. This document outlines a step-by-step guide to producing well-designed studies. The framework is based upon five main phases:

- Pre-clinical or theory
- Phase I – modelling
- Phase II – exploratory trials
- Phase III – main trial
- Phase IV – long term implementation and surveillance

This framework is highly applicable to CAM research where the earlier phases in this approach have sometimes been overlooked, causing invalid trial results. There was a call to inject more funds into this earlier phase work. The full text of the MRC document can be downloaded in PDF format from the MRC website, http://www.mrc.ac.uk/pdf-mrc_cpr.pdf.

4.4 Cancer Research UK (CRUK)

From the perspective of CRUK, it is clear that CAM is popular with the public. As CRUK relies entirely on public funds, it strives to be responsive and believes that topics in CAM represent a major new area that needs to be addressed. However, there is a lack of high quality information including systematic reviews, meta-analyses and patient information. There are potentially many possible funding streams for CAM research. An open door policy about talking with researchers at an early stage is crucial. The difficulties associated with trial design and methodology were highlighted, as well as the difficulties in achieving hard outcome measures, such as tumour response and survival.

4.5 Key priorities

Herbal medicine was identified as a key research priority. There are safety implications for its use, either when used alone or in terms of potential interactions when combined with conventional cancer therapies. Presenters stressed that CAM research will and should be judged against other

domains and therefore must be rigorous and of the highest quality.

Each of these presentations and discussions highlighted a common theme – that in order to move the field forward in a meaningful way, collaborative relationships, both national and international, are essential.

4.6 Panel discussion and questions

The panel discussion and questions raised by the audience highlighted many of the major issues faced by researchers in cancer CAM.

- Difficulties about how to choose and prioritise research topics within CAM and cancer care that warrant investigation
- Whether or not the research agenda should be driven by clinicians or users
- The importance of user involvement at the earliest stage of research was highlighted as a critical component of successful research into CAM and cancer
- It was suggested that users be involved in funding committees by increasing users on panels to ensure their perspective is heard and considered by funding committees
- The importance of pilot work and funding mechanisms to support such work
- Concerns about appropriate peer review within these funding bodies were raised. The panel acknowledged the challenges in finding reviewers with appropriate expertise to evaluate these proposals
- Reviewers attempt to apply conventional expertise to CAM topics and this raises particular concerns for proposals focused on particular therapies
- Representatives from the USA highlighted their practice of requesting and including an ad hoc reviewer with specific experience in the intervention under study

Another area of discussion was around the advantages and disadvantages of ring-fencing funds to support specific priority areas of CAM related research. The example given was that of the Department of Health recently setting aside funds for research into the drivers behind the use of CAM in cancer care. This produced many high quality proposals.

5 Specific Therapies

Experts in certain disciplines were asked to describe the major issues in their fields by using relevant examples. Issues related to the importance of demonstrating safety and were discussed in terms of the requirement to draw in funding. Suggestions were made about how to attract the right researchers for these topics.

5.1 Acupuncture

The reported effects of acupuncture are that it can have an analgesic effect, boost circulation and mood, as well as setting off immune system and autonomic responses. Overall, acupuncture, if practised by a skilled practitioner, is seen as a safe and effective complementary therapy to use in helping control certain side effects of cancer and its treatment (pain, nausea, breathlessness and xerostomia).

A major focus of the discussion about research and acupuncture is the need for infrastructure. Acupuncture research is an area in which the methodologies are relatively well developed. Therefore effort is concentrated on seeking out researchers, and for those interested in this topic to develop successful strategies for securing funding support.

5.2 Homeopathy

This therapy approach was used as an example to demonstrate the importance of research that includes a focus on the therapeutic power of consultation as well as an attempt to describe specific effects of treatment. Key questions to consider for research included whether this approach is clinically relevant and cost-effective.

A research strategy in homeopathy is needed and has implications for primary care, universities, CAM communities and cancer care communities. It should include both qualitative and quantitative research. The issue of available funding was also discussed.

5.3 Herbal medicine

The topic of research on herbal medicine was presented in the context of the current changes in the European Directive (products and practices statement). Major changes are underway as a result of the forthcoming regulation of herbal medicine practice. These changes have significant implications for research, as there are large numbers of users, and implications for pharmacological vigilance to protect consumers. The Medicines and Healthcare products Regulatory Agency website (www.mhra.gov.uk) was described and the short-term impact on current research efforts outlined. However, in the long-term, it was suggested that these changes could result in more rigorous and controlled research.

The quality and safety of products as well as the potential anti-cancer activity of medicinal plants and herbs need to be explored fully, as conflicting results in the literature should be carefully assessed.

5.4 Nutrition

There is a major focus in complementary cancer care practice on nutrition and using nutritional approaches to support patients undergoing cancer treatment. High quality research is urgently needed in this area. The public is confused by much of the available information. It was suggested that nutritional approaches might correct metabolic deficiencies, cut the risk of infection, improve quality of life, minimise side effects of conventional treatments, and perhaps prevent spread and recurrence of disease. The speaker suggested foods to avoid as well as those foods whose consumption should be increased. However, specific recommendations may be premature as additional research is warranted.

5.5 Nutraceuticals

This presentation highlighted early science on the use of nutraceuticals in the potential treatment of brain tumours and raised compelling questions for discussion. The presentation included data from promising laboratory work on micronutrients, particularly flavanoids, and their effects on cell lines.

5.6 Panel discussion and questions

Questions focused upon whether recommendations regarding herbal and dietary supplements are appropriate given the current level of research evidence available in some of the topics. The importance of and necessity for physicians and other practitioners to ask their patients what supplements they are taking requires more attention. Physicians need educating about the possible side effects of supplements, including the potential for some to interact with other treatments, such as chemotherapy. Without this knowledge it is difficult to feel confident about answering their patients' questions and gaining their trust in this area.

It was also suggested that the new licensing laws should help protect consumers. Some information resources were mentioned such as the invaluable *Information Resource: About Herbs, Botanicals & Other Products* which is part of the Memorial Sloan-Kettering Cancer Centre website, <http://www.mskcc.org/mskcc/html/11570.cfm>.

6 Research Issues and Themes: specific experiences

6.1 A research experience from the UK

The development of a research programme within the Oncology Centre at the Institute of Rehabilitation, University of Hull, using touch and mind-body techniques was described as an example of an integrated research programme for cancer care. The importance of a fully integrated service within oncology was stressed as critical to the successful development of such a programme, as it encourages patients to use the services, as well as providing opportunities to receive input from the oncology team. The presentation also focused on the use of these interventions in the supportive care of cancer patients, in that with appropriate training and organisation most psychological and psychiatric problems associated with cancer can be prevented. A great deal of distress is from cancer treatment rather than the disease itself, and the context in which CAM is provided can have a profound effect on outcome. At this specific research programme, staff are trained to elicit patient concerns and respond quickly and appropriately to them. A seamless service is critical for such a service to be successful.

A discussion of the importance of funding for this research focused upon the importance of the randomised controlled trial (RCT). RCTs will influence NHS funding as well as clinical practice. Patient demand should not be the only justification for providing funding in these areas. High quality RCTs, being pragmatic and exploratory, are also necessary to evaluate efficacy, effectiveness, safety and cost-effectiveness. In addition there needs to be a research focus on psychoneuroimmunology and the possible biological effects of therapies need to be taken into account.

In conclusion, the physical, functional and financial integration with other parts of the cancer centre is critical to the success of such a research programme. This integration helps to bridge the gap and maintain a patient-centred approach. This strategy also works well to support laboratory research.

6.2 Research experiences from the USA

Two representatives from the USA presented examples of research programmes developed at their institutions, which are:

- The Center for Integrative Medicine, University of Maryland, Baltimore; and
- The Department of Pain Medicine and Palliative Care, Beth Israel Medical Center, New York

The first presentation described the University of Maryland experience in developing centres of excellence in CAM research and related activities. It demonstrated how expertise developed in CAM research could be attracted and applied to cancer topics.

These centres can be seen as a new vehicle of health care based upon continuous healing relationships, which reflect the preferences and values of patients. Centres of excellence coordinate physicians across disciplines and emphasise collaborative relationships and a focus on rigorous science. Recommendations about developing such centres include the importance of conducting pilot studies; that research should progress in a stepwise progression; seeking out seed funding; creating a balanced portfolio so there is synergy across projects; and establishing links between academic centres and CAM communities to build research capacity.

Two examples of research partnership activities were then presented in more detail. A roadmap initiative in 2003 supported the development of research partnerships with defined groups of patients and community based providers and academic researchers. A newly created consortium of academic centres for integrative medicine is an example of such a partnership and reaffirms the importance of relationships between practitioners, patients and providers. The focus of care is on the

whole person and is guided by research evidence, making use of all appropriate therapeutic approaches to achieve optimal health and wellbeing.

Another example of a research partnership is the Practice Based Research Network, which was created to investigate outcomes in the clinical setting. For success, four interrelated elements are necessary: research, patient care, information and education. Therapies studied represented all CAM domains and featured a variety of disease types.

The speaker's own research programme is focused on pain and was used to illustrate some of the developmental steps in creating a research centre. For example, in CAM research on pain, RCTs are often premature. A stepwise progression of research projects such as acupuncture for the treatment of osteoarthritis pain, the importance of linking with other centres that treat the same disease and then the translation of the osteoarthritis research to cancer care was presented. The role of the NCI in the USA in attracting researchers in CAM and cancer was also highlighted.

The second USA presentation provided an example of a conventional cancer researcher, working in the Department of Pain Medicine and Palliative Care at Beth Israel Medical Center, New York, who is developing a research programme that applies his expertise to CAM-related research. Recommendations for the successful development of an integrative medicine programme at a conventional centre include seeking out assistance from funding organisations and using existing mechanisms to find enough support for initial start up of the programme. This can be a difficult and challenging process and collaboration is a necessity. In addition, the NCI's OCCAM was sought out as a source for specific guidance.

The importance of feasibility studies to ensure that patients will take part in the research was emphasised. In addition, the effect of building the programme into the orthodox structure on its ability to be used as a catalyst for other studies was presented. The inclusion of caregivers and families is also considered important in this programme.

7 Methodologies

7.1 The NCRI Complementary Therapies Clinical Studies Development Group

The Chair of the newly established Complementary Therapies Clinical Studies Development Group reported on their proposed plans. This new studies group was created with a broad remit including:

- Plans to review CAM research
- Establishing a competitive research portfolio
- Proposing and submitting rigorously designed studies
- Advising the NCRI on CAM research
- Reviewing and commenting on proposals

The main focus of the group is to submit high quality proposals and develop these in order to conduct good clinical studies. This studies group will also support the NCRI in seeking out and creating collaborations with UK, European and American research and governmental organisations. For more information please see the NCRI website at <http://www.ncri.org.uk/home>.

7.2 Design

This session raised the issue of how to identify and prioritise research areas as well as create the appropriate research design for each type of question. The discussion also stressed the importance of using mixed research methods by design rather than by accident and why it is preferable to design research that provides more answers than a simple 'yes' or 'no' to questions such as "does this treatment work?" Research designs should try to answer the 'how' and 'why' questions such as those that seek to demonstrate mechanisms of action or to identify specific patient groups that may benefit uniquely from a certain intervention. CAM research needs to use study designs that capture enhanced wellbeing, along with emotional and spiritual support.

Specific issues that need to be considered in creating CAM research study designs were

identified. They include patient preference; individualised care; practitioner effects; challenges when CAM approaches are provided in addition to usual conventional care; and that CAM may be accessed by choice.

In addition, it is important to note that the research culture is young within the National Health Service, as there are few clinical champions and most of the research culture is located outside the NHS. A collaborative research agenda that involves patients and CAM practitioners is needed.

have different priorities. The research agenda needs to include studies on practitioner effects and what those effects tell the research and practice communities about healthcare outcomes.

Panellists reaffirmed the necessity of rigorous scientific research designs in CAM, as extraordinary claims will only be accepted if validated by scientific evidence.

7.3 Measurement tools

The development of patient-centred measurement tools would help to progress research in complementary cancer care. We should find better ways of supporting cancer centres so they can carry out meaningful evaluations. An appropriate measurement tool is one that provides the data that are wanted and provides answers for what patients think is important. Furthermore, effective measurement tools must be sensitive to change as well as context-specific.

7.4 The placebo response

This session provided insight into the placebo response as part of CAM use. Potential mechanisms underpinning placebo responses were proposed and demonstrations of their importance were presented. Challenging questions were raised such as whether there are specific or common effects of interventions.

7.5 Panel discussion and questions

The discussion raised several issues related to the development of CAM research methodologies and research design. The panellists were also asked about how best to prioritise research questions. Responses included that the answer depends upon who is asking the question and who is answering it. Others suggested that patients should be asked about what they think is important and perhaps research that is most helpful should be a priority. The panel also stressed the importance of a team approach in CAM research as this challenges and provides additional points of view since patients

8 Users' and Clinicians' Perspectives

8.1 The user's perspective

This session provided updated research from interim studies of the drivers for use of CAM in cancer care. Additional findings have demonstrated that patients want to hedge their bets in that they tend to use a variety of CAM approaches. It was noted that surveys are difficult to interpret, as there are challenges with definitions of terms.

In addition, the participants were honoured to hear from two people affected by cancer who eloquently described their experiences. They raised several important issues for those who treat people with cancer, as well as those crafting the research agendas and conducting the studies. These presentations highlighted the fact that good practice in the delivery of complementary therapies derives from the following:

- They are integrated into mainstream treatment by being delivered on the same site with usage and access endorsed, facilitated and encouraged by the healthcare staff
- Courses of treatment are free to allow all to benefit from them
- A variety of therapies is offered, including relaxation and other self-help therapies
- Time can be dedicated to patients' emotional wellbeing, with a practitioner who is the same person throughout the treatment

The abstracts of the presentations by the two users are provided as Appendix D to this document.

8.2 The clinician's perspective

An oncologist who created a highly successful clinical programme presented recommendations for working out an optimal model of service delivery. This needs to include a lengthy

consultation process and training of the workforce. Therapies should be introduced slowly and a shared language and understanding needs to develop between CAM practitioners and conventional clinicians.

The conduct of research serves to boost credibility of the programme and centre, improves patient care, generates knowledge and fosters collaboration.

8.3 Panel discussion and questions

The panellists included oncologists, a surgeon, a general practitioner and a palliative care physician who presented their views on complementary cancer care approaches. When asked whether they, as clinicians, have asked their own patients about CAM use, the responses were mixed. It was pointed out that asking patients often depends on where a patient is in the treatment process. For example, having a discussion about CAM therapies was much more likely to be undertaken by a palliative care physician, when patients are in the later stages of their disease, than by a surgeon who mostly meets patients in the earlier diagnosis stage. Generally the panellists acknowledged that they would be willing to be much more engaged if there was more support and information on this area available to them.

The panellists agreed that if they are asked about CAM use they need to know the information in order to give their patients informative and reliable responses. Some panellists acknowledged that they did not understand some of the CAM concepts, but that it may not matter because as long as they know whether or not the therapy works and is safe, the actual mechanism of the therapy was not as important. Generally, they were broadly supportive of complementary therapies, including herbal medicines and nutritional supplements, as long as they knew the possible side effects and interactions between the therapies and conventional treatments. This is an area where there needs to be a real focus on development. However, recommending alternative therapies, such as stringent diet regimes, remains unacceptable until there is much more evidence-based scientific research to prove them.

It was also emphasised that patients want to be involved in their treatment. The clinicians expressed concerns, and highlighted that if things go wrong they are the ones who are held responsible, which was seen as a serious problem. However, members of the audience encouraged the panellists to continue to listen to their patients, if we are to have a truly consumer led system. Self-care is important and some questioned whether clinicians should interfere as patients have a need to act for themselves.

9 Developing Information

These presentations provided useful information on European and UK projects. Audience discussion shed light on other projects such as the Department of Health and Research Council for Complementary Medicine development of a complementary therapies database aimed at health professionals and patients. For more information please go to http://www.rccm.org.uk/static/Proj_NHS_priorities.aspx.

As highlighted in the earlier UK overview, the urgent need for more high quality information was stressed, and recommendations to share resources, specifically those in the USA, were presented. The focus of activity is on the dissemination of reliable information from reputable sources to patients, the general public and health professionals.

The audience also highlighted that, with the explosion of information available on the web, patients have access to an enormous amount of information about CAM. However, much of this information is not highly regarded and in some situations the information is clearly misleading and dangerous. There need to be reliable resources both for patients and health professionals to refer to. It was pointed out that developing the informatics helps expand clinical recommendations but in some areas we still have insufficient information to put these into clinical practice.

10 Conclusions and Recommendations

10.1 Conclusions

Complementary therapies in cancer care research can be viewed as a new science that brings disciplines together to investigate topics of highest priority to users, their families, physicians, practitioners and researchers. It is imperative that this new science remains patient-centred and continues to involve those affected by cancer. The research community must respond to the need for high quality information for patients, their families and their practitioners about the safety, efficacy, effectiveness and interaction of therapies. A research evaluation collaborative (network), involving multidisciplines, is needed to ensure that high quality research is implemented into clinical practice as soon as possible.

It is clear that the UK research and practice communities are not alone in their struggles. Stating that the goal of health care should be to be both comprehensive and evidence-based, a new report from the Institute of Medicine of the National Academies in the USA (2005) calls for conventional medical treatments and complementary and alternative treatments to be held to the same standards for demonstrating clinical effectiveness. In the report, titled *The Use of Complementary and Alternative Medicine in the United States*, the authors state:

“The same general research principles should be followed in evaluating both types of treatments, although innovative methods to test some therapies may have to be devised”.

The study was sponsored by the National Institute of Health and the Agency for Healthcare Research and Quality. The Institute of Medicine (IOM) is a private, nonprofits institution that provides health policy advice under a USA congressional charter granted to the National Academy of Sciences. The report was written to assist the National Institutes of Health (NIH) in developing research methods and

setting priorities for evaluating products and approaches within complementary and alternative medicine (CAM). The Chair of the IOM committee that issued this report stated that:

“Ideally, health care should be comprehensive, grounded in the best available scientific evidence, and centred on patients’ needs and preferences.”

In addition, the committee stressed that health professionals and patients should have sufficient information about safety and efficacy to take advantage of all useful therapies, both conventional and complementary and alternative.

10.2 Crafting a future agenda

The challenge now is how to apply what has been discussed and learned in terms of funding infrastructure, finding peer review, engaging experts from related and associated disciplines, providing technical assistance and identifying and creating new experts in the field. Examples from organisations such as the NCI can be used as models for creating initiatives and programmes that are designed specifically to meet the needs of the UK research and patient communities.

Furthermore, progress and programmes that have worked well in the UK can be used to inform not only USA colleagues but colleagues from around the globe. This symposium is an example of how we look to learn from each other to move the science and clinical practice forward. Multidisciplinary and multinational collaboration are essential for the benefit of all cancer patients.

10.3 Recommendations

The symposium highlighted several major areas in complementary therapies and cancer in the UK that need attention. In order to move forward in these areas, the participants identified the following needs:

- To hold CAM research to the same standards of scientific rigour as other orthodox medical care
- An evidence-base for clinical decision making
- An infrastructure and funding opportunities to develop the evidence
- Technical assistance to be competitive for those funding opportunities

- To encourage funding bodies to support exploratory work
- To learn from models that already exist, for example making a template of the OCCAM workshops that address how to write more successful grant applications
- To develop a plan to prioritise areas of research
- To identify methodologies appropriate to research questions including the use of mixed method research
- Interdisciplinary teams including researchers, health professionals, complementary therapy practitioners and users sharing their expertise
- To develop an advisory board that would be able to provide information to newcomers in the field
- To match physicians and other healthcare professionals with appropriate research projects
- Research issues should be patient-centred
- To improve and disseminate high quality information on CAM and cancer across the spectrum of those involved: doctors, nurses, patients and therapy practitioners, etc.
- More education for doctors about the importance of asking their patients what therapies and supplements they are using, as well as how best to advise them

The recommendations reflect the range of themes which were highlighted by speakers and participants. However, the overriding message was the necessity for collaboration and communication across many fields and disciplines. The concept which united all those who took part in the symposium was the belief that we all share the same goal of moving science and practice forward to benefit cancer patients and their families.

Appendix A. Useful Resources

A.1 Charities and other organisations

United Kingdom

Breakthrough Breast Cancer

Weston House, 3rd Floor, 246 High Holborn
London WC1V 7EX
Tel: 020 7025 2400
Email: info@breakthrough.org.uk
Website: <http://www.breakthrough.org.uk>

Bristol Cancer Help Centre

Grove House, Cornwallis Grove
Bristol BS8 4PG
National helpline: 0845 123 23 10
Centre reception: 0117 980 9500
Email: helpline@bristolcancerhelp.org or
info@bristolcancerhelp.org
Website: <http://www.bristolcancerhelp.org>

Cancer Research UK (CRUK)

P.O. Box 123, Lincoln's Inn Fields
London WC2A 3PX
Tel (Customer Services): 020 7121 6699
Tel (Switchboard): 020 7242 0200
Website: <http://www.cancerresearchuk.org/>
Patient information website: CancerHelp UK,
www.cancerhelp.org.uk

Department of Health (DOH)

Richmond House, 79 Whitehall
London SW1A 2NL
Tel: 020 7210 4850
Email: dhmail@dh.gsi.gov.uk
Website: <http://www.dh.gov.uk>

Macmillan Cancer Relief

89 Albert Embankment
London SE1 7UQ
Freephone: 0808 808 2020
Email: cancerline@macmillan.org.uk
Website: <http://www.macmillan.org.uk/>

Marie Curie Cancer Care

89 Albert Embankment
London SE1 7TP
Tel: 020 7599 7777
Website: <http://www.mariecurie.org.uk/>

Medical Research Council (MRC)

20 Park Crescent
 London W1B 1AL
 Tel: 020 7636 5422
 Email: corporate@headoffice.mrc.ac.uk
 Website: <http://www.mrc.ac.uk/>

National Cancer Research Institute (NCRI)

PO Box 123, 61 Lincoln's Inn Fields
 London WC2A 3PX
 Tel: 020 7061 8460
 Email: info@ncri.org.uk
 Website: <http://www.ncri.org.uk>

Further details about the NCRI Complementary Therapies Clinical Studies Development Group's activities are available from Dr Eileen Loucaides
 Tel: 020 7061 8582 Email: ncriscsg@cancer.org.uk

The Prince of Wales's Foundation for Integrated Health

12 Chillingworth Road
 London N7 8QJ
 Tel: 020 7619 6140
 Email: info@fihealth.org.uk
 Website: <http://www.fihealth.org.uk>

Research Council for Complementary Medicine (RCCM)

c/o 1 Harley Street
 London W1G 9QD
 Email: info@rccm.org.uk
 Website: <http://www.rccm.org.uk>

**United States of America
 National Cancer Institute (NCI) Office of Cancer Complementary and Alternative Medicine (OCCAM)**

Office of Cancer Complementary and Alternative Medicine (OCCAM)
 National Cancer Institute, NIH
 6116 Executive Plaza North, Suite 609, MSC 8339
 Bethesda, Maryland 20852
 Email: ncioccam1-r@mail.nih.gov
 Website: <http://www.cancer.gov/cam>

National Center for Complementary and Alternative Medicine (NCCAM) - National Institutes for Health (NIH)

NCCAM Clearinghouse, P.O. Box 7923
 Gaithersburg, MD 20898
 Tel(international): 301-519-3153

E-mail: info@nccam.nih.gov
 Website: <http://nccam.nih.gov>

A.2 Useful websites not included in the list above

The American Cancer Society, *Complementary and Alternative Therapies*.

http://www.cancer.org/docroot/ETO/ETO_5.asp?sitearea=ETO

CAM on PubMed.

<http://www.nlm.nih.gov/nccam/camonpubmed.html>

CancerHelp UK Trials Database.

<http://www.cancerhelp.org.uk/trials/trials/default.asp>

DIPEX is a website of personal experiences of health and illness plus reliable information on treatment choices and where to find support.

<http://www.dipex.org>

Institute of Medicine. <http://www.iom.edu/>

M. D. Anderson Cancer Center's *Complementary/Integrative Medicine Education Resources* (CIMER) website is offered to help patients and physicians decide how best to integrate such therapies into their care.

<http://www.mdanderson.org/departments/cimer/>

The Medicines and Healthcare products Regulatory Agency (MHRA) website. www.mhra.gov.uk

Memorial Sloan-Kettering Cancer Centre, *About Herbs, Botanicals & Other Products*.

<http://www.mskcc.org/mskcc/html/11570.cfm>

The National Cancer Institute, *Complementary and Alternative Medicine*.

<http://www.nci.nih.gov/cancertopics/treatment/cam>

National Cancer Research Network (NCRN) *Trials Portfolio Database*.

<http://www.ncrn.org.uk/Portfolio/database.asp>

Research Council for Complementary Medicine (RCCM) and NHS complementary therapies database (CAMEOL).

http://www.rccm.org.uk/static/Proj_NHS_priorities.aspx

A.3 Publications

Buscher Jr, L F. *Everything You Wanted to Know About the NCI [National Cancer Institute] Grants Process....but Were Afraid to Ask*. NIH Publication No.02-1222, revised ed. National Institutes of Health, April 2002.
<http://www3.cancer.gov/admin/gab/index.htm>

Department of Health. *Government Response to the House of Lords Select Committee on Science and Technology's Report on Complementary and Alternative Medicine*. CM 5124. The Stationery Office, 2001.

House of Lords Select Committee on Science and Technology. *Complementary and Alternative Medicine*. HL Paper 123. The Stationery Office, London, November 2000. This document can be read online at <http://www.parliament.the-stationery-office.co.uk/pa/ld199900/ldselect/ldsctech/123/12301.htm>

Institute of Medicine (US). Committee on the Use of Complementary and Alternative Medicine by the American Public Board on Health Promotion and Disease Prevention. *Complementary and Alternative Medicine in the United States*. National Academies Press, 2005. At present it can be read free online by going to <http://www.nap.edu/catalog/11182.html> or purchased online at www.nap.edu

Kohn, Dr M. *Complementary therapies in cancer care*. Macmillan Cancer Relief 1999

MRC Health Services and Public Health Research Council. *A Framework for Development and Evaluation of RCTs for Complex Interventions to Improve Health*. Medical Research Council, 2000. The full text of this document can be downloaded in PDF format from the MRC website
http://www.mrc.ac.uk/pdf-mrc_cpr.pdf

Office for Complementary and Alternative Medicine. *Strategies for Success: How to Write a Grant in Cancer CAM Research*. National Cancer Institute Office of Cancer Complementary and Alternative Medicine. National Institutes of Health, Bethesda, Maryland, 2003. Available through the Office for Complementary and Alternative

Medicine(OCCAM) or it can be downloaded from the OCCAM website:
<http://www.cancer.gov/cam/attachments/howtowrite.pdf>

Office for Complementary and Alternative Medicine Expert Panel on Symptom Research. *Expert Panels in Cancer CAM Research: Developing the State of the Science in Research Methodologies. Expert Opinions on Methodology: Development of Cancer CAM Symptom Research* [Final report]. National Cancer Institute Office of Cancer Complementary and Alternative Medicine. National Institutes of Health, Bethesda, Maryland, 2001.
<http://www.cancer.gov/cam/attachments/expert-panel-report.pdf>

Office of Behavioral and Social Sciences Research. *Qualitative Methods in Health Research: Opportunities and Considerations in Application and Review*. NIH Publication No. 02-5046, National Institutes of Health, 2001.
<http://obsr.od.nih.gov/Publications/Qualitative.PDF>

National Institute for Clinical Excellence (NICE). *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer. The Manual*. National Institute for Clinical Excellence, March 2004. This document can be downloaded in pdf format from:
www.nice.org.uk/page.aspx?o=110007

Tavares, M. *National Guidelines for the Use of Complementary Therapies in Supportive and Palliative Care*. The Prince of Wales's Foundation for Integrated Health, 2003. This document can be downloaded in PDF format from The Prince of Wales's Foundation for Integrated Health website:
http://www.fihealth.org.uk/fs_publications.html

Appendix B. Symposium Programme

| | | |
|---|---|---|
| Overviews | The UK The National Cancer Institute, USA | Dr. Michelle Kohn Dr. Jeffrey White |
| Infrastructure and Funding Research | The National Cancer Research Institute DOH R&D Research Capacity Programme | Dr. Liam O'Toole Dr. Lisa Cotterill |
| Views from the Funders | The Medical Research Council Cancer Research UK | Dr. Chris Watkins Dr. Richard Sullivan |
| Panel Discussion | Dr. Wendy B. Smith, Dr. O'Toole, Dr. Cotterill, Dr. Watkins, Dr. Sullivan | |
| Research Issues and Themes | | |
| Part 1: Specific Therapies | Acupuncture Homeopathy | Dr. Jacqueline Filshie Dr. Elizabeth Thompson |
| Part 2: Specific Therapies | Herbal Medicine Nutrition Nutriceuticals | Dr. Jo Barnes & Michael McIntyre Dr. Marilyn Glenville Dr. Harcharan Kaur Rooprai |
| Part 3: Development of Research Programmes | A Research Experience from the UK A Research Experience from the USA | Dr. Leslie Walker Dr. Ricardo Cruciani |
| Developing Centres of Excellence: | Progress in the USA | Dr. Brian Berman |
| Keynote address | HRH The Prince of Wales | |
| Part 4: Methodologies | NCRI & Clinical Studies Development Group Study Design Measurement Tools The Placebo Response | Dr. Susie Wilkinson Kate Thomas Dr. Charlotte Paterson Prof Michael Hyland |
| Panel Discussion | Dr. George Lewith, Dr. Berman, Ms. Thomas, Dr. Paterson, Prof Hyland, Dr. Wilkinson | |
| The User's Perspective | The Drivers for use of CAM in Cancer Care The Patient's Voice | Prof Jessica Corner First patient speaker & Mrs Sheila Smith |
| The Clinician's Perspective | Dr. Jane Maher | |
| Panel Discussion: Clinician's Perspective | Dr. Maher, Dr. Rob Thomas, Dr. John Omany, Dr. Andrew Sikorski, Dr. Maurice Slevin, Mr. Richard Sainsbury | |
| Developing Information | CAM and Cancer Europe CAM and Cancer Europe: Ongoing Research | Stephane Lejeune Prof Edzard Ernst |
| Crafting a Future Agenda | Discussion, Challenges and Collaborations? | Dr. Michelle Kohn |

Appendix C. Speakers and Session Chairs

Biographical details are included in the abstracts

Joanne Barnes

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Professor, School of Medicine, Health
Policy & Practice
University of East Anglia
Norwich, UK

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Professor of Cancer and Palliative Care
University of Southampton's School
of Nursing and Midwifery
Southampton, UK

Lisa Cotterill

Assistant Director
NHS R&D Research Capacity
Programme
Leeds, UK

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Exeter, UK

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Royal Marsden Hospital
Sutton, Surrey, UK

Marilyn Glenville

Nutritional Therapist
Tunbridge Wells, UK

Russell Hamilton

Deputy Director, Research and
Development
Department of Health
Bristol, UK

Christopher Head

Chief Executive
Bristol Cancer Help Centre
Bristol, UK

Michael Hyland

Professor of Health Psychology
University of Plymouth
Plymouth, UK

Michelle Kohn

Symposium Chair and
Complementary
Therapies Medical Advisor
Macmillan Cancer Relief
London, UK

Stephane Lejeune

CAM-CANCER Project Coordinator
European Organisation for Research
and Treatment of Cancer
Brussels, Belgium

Jane Maher

Consultant Clinical Oncologist
Mount Vernon Cancer Care Centre
Senior Lecturer at University College
Director, Lynda Jackson Macmillan
Centre
Chief Medical Office, Macmillan
Cancer Relief
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Chair
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Association
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Baroness Delyth Morgan

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Breast Cancer
London, UK

Liam O'Toole

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National Cancer Research Institute
London, UK

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Practitioner
MRC HSR Collaboration
Bristol, UK

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International Office and Education
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Bristol, UK

Lesley Walker

Head of Information
Cancer Research UK
London, UK

Leslie G. Walker

Professor of Cancer Rehabilitation
University of Hull
Director, Institute of Rehabilitation
Hull, UK

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Clinical Trials Programme Manager
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Bethesda, MD, USA

Susie Wilkinson

Head of Palliative Care Research
Marie Curie Cancer Care
London, UK

Appendix D. The User's Perspective: abstracts

The patient's perspective on using complementary therapies during cancer care

D.1 First speaker

My medical notes described me as '46 F secondary adenocarcinoma and unlocated primary'. I described myself as quite anxious, but concerned to conceal my anxiety, partly out of fear that my doctors might not tell me the truth about my situation. However, the reality is that who we are is much greater than the labels that we or our doctors give us.

I was fortunate, in that my hospital encouraged the use of complementary therapies: Charing Cross Hospital offered all cancer patients, free of charge, a set number of aromatherapy and reflexology treatments, and an unlimited number of relaxation classes, in order to improve patients' quality of life.

I was told about the service at my first chemotherapy treatment. Although I had been very sceptical about complementary therapies before my cancer diagnosis, I took up the offer and the nurses completed a referral form. The fact that the hospital provided this service showed that the doctors valued complementary therapies and would not criticise me for using them. It therefore felt safe to experiment. The classes being free made them easily accessible, as did their location in the hospital. I tried both aromatherapy and reflexology, and went to as many relaxation classes as I could.

The therapies, though very different from each other, provided the same benefits: they were life-enhancing, relaxing, boosted my feelings of self-worth, offered me a way to take responsibility for my own health, helped me cope better with the orthodox treatments, and gave me an opportunity to talk about – and thereby make sense of – what I was going through. The sessions provided TLC and reassurance – especially because I had the same therapist throughout all the sessions. (Whereas in eight months of conventional treatment, I saw eight different doctors.) The therapies made me feel better both physically and emotionally, and reduced my levels of stress and anxiety. The relaxation

sessions equipped me with a tool I could put to use in a variety of settings and, at the non-physical level, I learned to accept and let go in other areas of my life. I also dealt with 'unfinished business' which I do not believe I would have recognised or addressed if I had not had aromatherapy massage.

The provision of the therapy sessions felt like an investment in my care by the hospital, and particularly by the complementary therapists (who could give me more time and attention than the doctors). The clear message was that patients matter enough to be nurtured, and to have time devoted to them. This helped me believe that I was deserving of care; that I was of value.

The therapies provided me with a way to take responsibility for my own health. I found I could cope better with conventional treatments, learning through relaxation and visualisation how to replace my negative attitude to radiotherapy with a positive one. Perhaps my daily practice of visualisation accounts for the fact that at the end of my radiotherapy I had no visible skin damage.

Being able to talk to someone at each session helped me to understand my experience and come to terms with it. I could both integrate the facts of my situation and, at the same time, detach myself from my experience and not be submerged by it.

Such was the value I placed on my experience of complementary therapies that I decided to train in aromatherapy massage myself, so that I can offer to others the therapy which had done me so much good. I now work in Charing Cross Hospital as a member of the complementary therapies team.

Key Points

Good practice in the delivery of complementary therapies derives from the following:

- They are integrated into mainstream treatment by being delivered on the same site with usage endorsed and access encouraged and facilitated by the healthcare staff
- Courses of treatment are free to allow all to benefit from them
- A variety of therapies is provided, and relaxation and other self-help therapies are offered
- Time can be dedicated to patients' emotional wellbeing, with a practitioner who is the same person throughout the treatment

D.2 Second speaker: Sheila Smith

With a professional background in radiotherapy, mammography and breast imaging, my own diagnosis of breast cancer came as a considerable shock. I was not encouraged to question the treatment I was offered, but my professional training gave me access to technical and research information. This helped me to make an informed choice about my treatment. What I did not have, however, was emotional support (other than from family and friends) and no encouragement to do anything to help myself.

Fortunately I was already aware of the Bristol Cancer Help Centre, which offered insights into all aspects of healing of the mind, body, spirit and emotions, and which focused on helping people to find the right path for themselves on their cancer journey. At Bristol I learned visualisation techniques which helped me to deal with my fear of radiotherapy. Counselling provided me with insight into the way I led my life, which in turn led me to change aspects of what I did and how I behaved. I joined a support group, visited a nutritionist, arranged hypnotherapy sessions, and attended an assertiveness course. I undertook further relaxation and visualisation sessions on a pilot programme run by the Cavendish Centre in Sheffield.

Then by chance I discovered shiatsu, which helped me cope with severe pain and exhaustion following radiotherapy. I started to attend shiatsu sessions regularly, and the pain and lethargy went. I became fascinated with shiatsu and Traditional Chinese Medicine and also studied Chinese meditation. Further opportunities caused me to explore all self help approaches and make small changes in my life. However, I remained most drawn to shiatsu, and undertook training to qualify as a shiatsu practitioner.

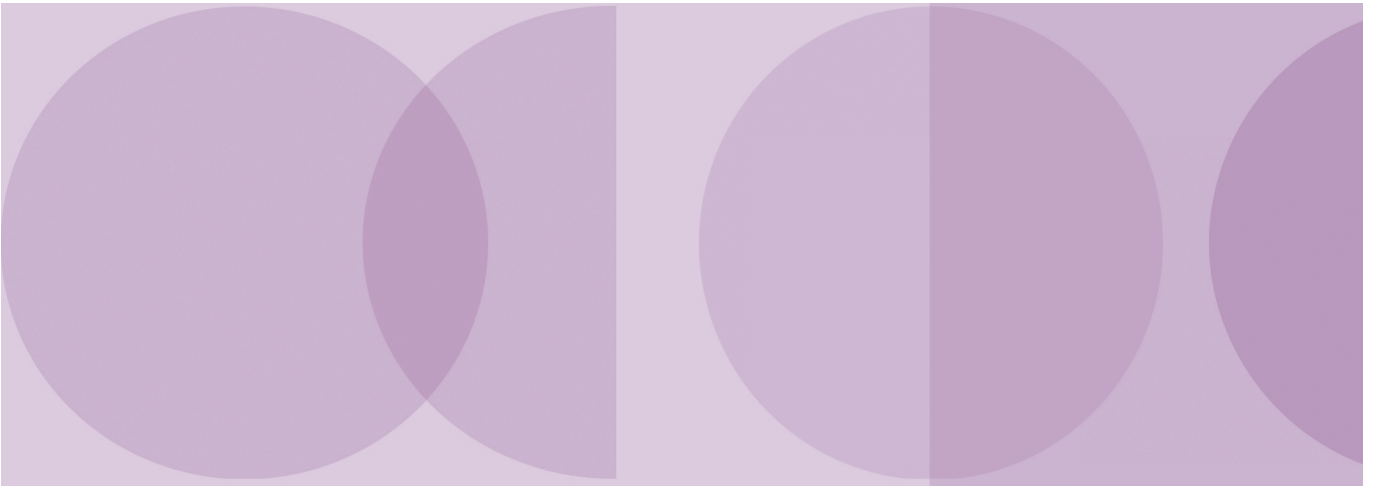
A recurrence of my breast cancer caused me to prepare myself mentally for death. But in fact life went on! New life experiences and support from complementary therapists and empathetic clinicians kept me going. I was inspired to run workshops on managing change; I undertook training in acupuncture and studied Thai massage. I established a Healthy Living and Cancer Support Centre in Anglesey offering shiatsu and information on orthodox and complementary approaches. This included my own assessment of what are the most and least effective ways of providing support to people affected by cancer.

My experience of Traditional Chinese Medicine has helped me to understand more about my own patterns of imbalance. It has taught me how to find solutions for myself, embrace change and take responsibility for my health.

Most patients want research to change things now, not in the future, with a focus on prevention rather than cure. Research must take into account individual needs and preferences and evaluate what is the right approach for each person. Patients should be encouraged to recognise that using complementary approaches provides an opportunity to take responsibility for their own health. However, it is vital that complementary and orthodox medicine are integrated in order to deliver care which is in the best interest of patients. It is by working in partnership that we will achieve true patient-centred care and work to the best possible outcomes for people affected by cancer.

Key points

- There is no single intervention which can be universally applied: individuals should find the therapy which best meets their needs
- Complementary therapies:
 - have a focus on prevention, wellbeing, harmony and balance
 - focus on the interconnectedness of mind, body, spirit and emotions
 - focus on the person as a whole and their interaction with the environment
- Many complementary therapies can be low-cost, effective ways of removing fear, inspiring hope and empowering patients
- Complementary therapies and orthodox medicine should be integrated in the best interests of patients



COMPLEMENTARY THERAPIES AND CANCER CARE: **Report of the Research Symposium**

Organised by the Complementary Cancer Care Charities Partnership

24-25 June 2004
London

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